



Mealtime support for adults with intellectual disabilities: Understanding an everyday activity

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Funding information

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Research of Patient Benefit programme (grant reference PB-PG-0906-11098). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Abstract

Background: Mealtime support has a direct bearing on the diet-related health of men and women with intellectual disabilities as well as opportunities for expressing dietary preferences.

Method: Semi-structured interviews with a sample of direct support staff providing mealtime support to adults with intellectual disabilities.

Results: When managing tensions between a person's dietary preferences and ensuring safe and adequate nutrition and hydration, direct support staff are sensitive to a wide range of factors. These include the following: clinical advice; service users' rights to choose; their (in)capacity to weigh up risks; how service users communicate; the constituents of a healthy diet; and a duty to protect service users' health.

Conclusions: Those responsible for setting standards and regulating the care practices need to look beyond too simple ideas of choice and safety to recognize ways in which providing support at mealtimes is a complex activity with serious consequences for people's health and well-being.

KEYWORDS

dysphagia, eating and drinking, healthcare, social care

1 | INTRODUCTION

As more adults live longer with age-related infirmities and lifelong disabilities, public concern over the quality of the care and support they receive has grown (Nelson, 2015). This paper explores the constituents of competent care through a study of the mealtime assistance that direct support staff (DSS) provide to men and women with intellectual disabilities. Mealtimes provide a powerful focal point for considering what constitutes competent care; for as well as ensuring safe and adequate nutrition and hydration, DSS should also facilitate opportunities for the expression of dietary preferences (Department of Health 2001). For men and women with intellectual disabilities, these considerations are of particular importance. Swallowing problems (dysphagia) are prevalent in this population

(Ball et al., 2012), while mealtimes may be among the few occasions where people have an opportunity to express and enjoy their preferences (Schwier & Stewart, 2005). For DSS providing mealtime assistance, these two imperatives, safety and autonomy, can, however, come into conflict, as when, for example, a person wishes to eat something that may cause them to choke or aspirate. The practical actions taken to address such dilemmas will have a direct bearing on the quality of the care and support being provided. Others' concerns over safety often result in people with intellectual disabilities having their autonomy restricted. Yet, with respect to eating and drinking, aspiration-related respiratory illnesses are the leading cause of premature deaths (Tyrer & McGrother, 2009) and of avoidable admissions to hospital (Glover & Evison, 2013). Moreover, rates of obesity and life-threatening low weight are much higher in this population

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than in the general population (Emerson, Baines, Allerton, & Welch, 2010). It would seem, therefore, that in this population, where many people receive support with eating and drinking, something could be going awry. Examining the details of mealtime assistance may, therefore, present a fruitful avenue for reflecting on the quality of the care and support provided by DSS, as well as for considering how to reduce the incidence of diet-related ill-health in this population.

Although focused on England, the research reported and discussed here is likely to have relevance in all countries and jurisdictions where adults with intellectual disabilities receive support from DSS.

2 | BACKGROUND

In the United Kingdom, some 15% of adults known to specialist intellectual disability services receive mealtime assistance for a range of difficulties, including swallowing problems, known as dysphagia; the absence of independent feeding skills; and behavioural/psychological problems (Ball et al., 2012). Interventions to address these difficulties are usually under the direction of a speech and language therapist (SLT) (Marriott & Turner, 2013), but it is DSS who typically have day-to-day responsibility for implementing any interventions. Potential interventions include (a) managing the pace at which meals are eaten by prompting the chewing of food to minimize the risks of choking or aspiration; (b) avoiding certain foods or modifying their consistency, again, to minimize the risk of choking or aspiration; (c) ensuring people adopt a posture that maximizes the effectiveness of their swallow; (d) adapting the mealtime environment to aid concentration; and (e) providing adapted cutlery and crockery so that, where possible, people can feed themselves (Marriott & Turner, 2013). Research suggests that while DSS are following guidelines concerning modifications to the consistency of food and fluids (by blending and adding thickeners), they struggle with the more intimate and fine-grained interventions, like prompting people to chew their food and eat it more slowly (Chadwick, Jolliffe, Goldbart, & Burton, 2006). There are concerns that adults who live in community residential services are not eating nutritionally balanced diets (Hamzaid, O'Connor, & Flood, 2020; Robertson et al., 2000) and that a significant proportion of their energy consumption comes from snacks consumed between meals (Adolfsson, Sydner, Fjellstrom, & Andersson, 2008). Moreover, research suggests that nutritional knowledge among DSS is poor (Hamzaid, Flood, Prvan, & O'Connor, 2018). Despite an association between the incidence of obesity and practices to respect people's dietary preferences (de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012), ensuring that people can choose what they eat is presented as an essential standard for residential services in the UK (CQC, 2010). Moreover, controlling or restricting the diets of adults with intellectual disabilities is seen as infantilizing them (Davies, 2007). In this context, the quality of the mealtime assistance provided by DSS will have a direct bearing on both the diet-related health of men and women with intellectual disabilities (Adolfsson, Fjellström, Lewin, & Mattsson

Sydner, 2012; Ptomey, Goetz, Lee, Donnelly, & Sullivan, 2013) and their well-being (Schwier & Stewart, 2005).

3 | METHOD

To examine the mealtime assistance provided by DSS and to begin to consider how to assess the quality of this assistance, a sample of DSS working in the East of England (the county of Cambridgeshire and the parliamentary constituency of North East Essex) were recruited. This area is diverse, comprising variations in affluence and deprivation as well as urban and rural settings. There are an estimated 174 providers in community residential services in this region, for a total population of 5,383 persons known to specialist services, of whom 142 took part in an exploratory, prospective cohort study of adults identified as needing assistance with eating and drinking (Perez et al., 2017). DSS were eligible for inclusion if they had provided mealtime support to an adult with an intellectual disability who had taken part in an earlier study to estimate the extent and nature of such support (Ball et al., 2012). Using a consent process approved by the National Research Ethics Service (www.hra.nhs.uk), opportunity sampling, dividing contacts evenly between the county of Cambridgeshire and the parliamentary constituency of North East Essex, led to the recruitment of 19 DSS (14 females) working in 18 different community residential services. No claims can be made about the representativeness of this sample with respect to sex or experiences, in relation to the wider population of DSS. The topic guide for the semi-structured interviews explored the practicalities of ensuring safe and adequate nutrition and hydration while also respecting a person's dietary preferences. More specifically, prompts were used to ask respondents to describe the assistance a particular individual needed; the risks of not providing that assistance; whether that assistance affected the person's enjoyment of their food; and what opportunities the person had to choose their own food. The interviews were conducted in the residential services where the DSS worked, lasted between 40 and 80 minutes and were audio-recorded. These recordings were transcribed verbatim. An initial thematic coding (Braun & Clarke, 2006) of these data using NVivo revealed 36 separate incidents (across 19 interviews), in which DSS described responding to tensions between a service user's dietary preferences and interventions designed to safeguard their health. These incidents fell into three broad themes that, not surprisingly, reflect the areas of interest reported in the research literature. Namely, concerns over aspiration and choking (Glover & Evison, 2013; Tyrer & McGrother, 2009), undernutrition (Emerson et al., 2010) and dietary choices thought likely to cause an unhealthy gain in weight (Adolfsson, et al., 2012). From these 36 incidents, six excerpts have been chosen for detailed examination, two examples from each of the three accounts of concerns.¹ This choice is necessarily idiosyn-

¹Three instances of persons with behavioural/psychological problems that disrupted orderly eating and drinking were reported, but these have been excluded from the analysis presented because they did not involve a tension between protecting a person's health and honouring their wishes.

cratic but was based on a judgement about the chosen excerpts being “fuller” than others, in the sense that the DSS concerned describe, even if succinctly, not only their actions but also their thinking behind those actions. Consequently, the analysis presented below is not comprehensive in terms of detailing all predictable events; rather, it serves to demonstrate some of the ways in which DSS are approaching tensions between promoting safety and autonomy at mealtimes.

That said, there are long-standing concerns over the use of interview data as a reliable means for accessing a respondent's actions and associated thoughts (Cicourel, 1964). This is because what is reported in research interviews is rooted in the contingencies of an interaction between interviewer and interviewee (Mishler, 1991). One way to address this is to see spoken utterances as *actions*, in which speakers pursue particular strategic purposes (Potter, 1996). So, while interview data do not offer a window onto past events and thoughts, it can tell us something about how these DSS are defining “good practice,” assuming, that is, that these respondents used the interviews as an opportunity to project an image of themselves as “competent” support workers (Silverman, 2001). It is this rhetorically constructed image of care practices that is used to explore and consider the constituents of good care.

Each excerpt is introduced with a description of the speaker: employment status (support worker, senior support worker or house manager) and the total number of years spent supporting people with intellectual disabilities. In addition, where a specific service user is discussed, a brief description of that person is included: age; severity of intellectual disability (mild, moderate or severe); and level of communication (verbal; limited communication; no communication). Pseudonyms are used throughout.

4 | FINDINGS

The six chosen data excerpts are presented under the three headings identified above: risks of choking and aspiration; undernutrition through refusals to eat; and unhealthy choices.

4.1 | Risks of choking and aspiration

Mandy, with 2 years' experience of support work, reports that Mr Graham Davies “loves his toast” notwithstanding the risk of choking. Hearing about this risk prompts the interviewer to enquire about the difficulties of denying him something he loves (see Box 1, Excerpt 1). Mandy responds by describing what she styles as a “compromise.” The advice from the SLT is formulated as discretionary (“try”) rather than categorical (“don't”); the sense of loss resulting from not eating toast is graded as comparable to being denied chocolate; and Mr Davies' right to eat what he likes is asserted, even while acknowledging that he “often chokes.” Mandy's account combines respecting service user choice with a responsibility to protect Mr Davies from harm, although it is debatable whether her “compromise” would win

Box 1 Risks of Choking and Aspiration

Excerpt 1:

Mandy: Yeah, they [the SLT] didn't say, ‘You can't give him toast.’ They said ‘Try and avoid these types of foods’. So what we've done, rather than avoiding them we've compromised, whereas we've cut the toast up smaller ... we feel that Graham's able to eat with... he has a member of staff with him while he has his breakfast so he has support there rather than him not having the toast at all. It's like saying to you: ‘You're not allowed chocolate any more’ <Laughter> [...] Graham's got a right to have toast because he likes toast. So even though he knows that he often chokes on it he still has a right to have it. [56 years old; mild learning disability; verbal communication]

Excerpt 2:

Rosa: So in the last few months I've been to certain meetings [with the SLT] with Sally to gauge her level of mental capacity, because if it's concluded that she has the capacity to weigh-up the potential risks [of not thickening her drinks] and how she feels about *Thick And Easy*, and she still decides she doesn't want it, then it's her choice; if she has the capacity to choose. [38 years old; moderate learning disability; verbal communication]

widespread approval, given that Mr Davies is reportedly choking on his toast. Excerpt 2 (see Box 1) concerns Rosa, a senior support worker with 4 years' experience, who has also received advice from a SLT. Yet, despite repeated objections from Ms Sally Jones, Rosa and her colleagues, in compliance with the advice they have received, are thickening her drinks. Ms Jones' objections go unheeded because of uncertainty over her capacity to make an informed choice (see Box 1, Excerpt 2). Rosa explains that despite Ms Jones' objections, her drinks are thickened because of ongoing uncertainties over her “capacity to weigh-up the potential risks.” If it is determined that Ms Jones has capacity, “and she still decides she doesn't want it [thickener added to her drinks], then it's her choice.” Rosa's account while honouring the right of service users to make their own decisions constructs that right as conditional upon having the capacity to weigh up the potential risks. And until the issue of Ms Jones' capacity is finally resolved, staff continue to override her wishes and so act to protect her from potential harm. Rosa's account is broadly in line with the *Mental Capacity Act 2005 (England & Wales)*, which asserts the legal autonomy of people with mental disabilities to make their own decisions if they are judged to have capacity. Where her account contravenes the Act is in the decision to override Ms Jones' objections prior to determining her capacity: the first principle of the Act is that capacity be assumed unless it is established otherwise.

Excerpts 1 and 2 differ with respect to the actions that Mandy and Rosa take following advice from a SLT. Mandy's “compromise” ensures that Mr Davies continues to have the toast he purportedly

loves, albeit cut up into smaller pieces and with the attendant risk that he might choke. In contrast, Rosa follows the advice of the SLT and thickens Ms Jones' drinks. Rosa justifies the decision to override Ms Jones' objections by referencing uncertainties over her capacity. Respecting Ms Jones' wishes given the risks this might entail depends on establishing her capacity to make an autonomous decision. Until her capacity is established, however, Ms Jones' wishes are being overlooked. Where Excerpts 1 and 2 are similar is that both Mandy and Rosa invoke a service user's right to make their own choices and their own responsibility to protect that service user from potential harm.

4.2 | Refusals to eat and the risk of undernutrition

In Excerpt 3 (see Box 2), Martha, who has 4 years' experience of care work, explains that Mr Eric Preston either has his food chopped up or blended. This observation prompts the interviewer to ask whether he has a choice over this (see Box 2, Excerpt 3). Martha equates Mr Preston's refusals to eat as both a choice and a request: a request for the same food blended or to go straight to a pudding without a savoury main course. Although this formulation is congruent with the value placed on service user choice, it is a little cryptic as to precisely how repeated refusals to eat can be seen as Mr Preston *choosing* to "go straight to the pudding," other than, *post eventum*, when he eats the pudding. In Excerpt 4 (Box 2), Julie, with a year's DSS experience, reports that Mr Shaw has a habit of pushing his food away (see Box 2, Excerpt 3). Julie characterizes supporting Mr Shaw as "playing these games". Games in which she repeatedly presents and re-presents his food in different configurations "until you find the one that's appropriate for that day", and Mr Shaw eats. The idea of "playing" stands in stark contrast to the interviewer's suggestion that Mr Shaw is "manipulating you." Faced with food refusal, and the possibility of undernutrition, Excerpts 3 and 4 show rather different formulations of the problem. Martha characterizes these refusals as expressions of "choice," which rhetorically aligns the assistance she provides with disability policy, whereas Julie describes them as "games". While not an explicit policy goal, game playing does at least soundfriendly and interactive. In both cases, the practical upshot is that Mr Preston and Mr Shaw are eating, although Mr Preston's diet may not be particularly healthy if he regularly eats only puddings. Noticeably absent from these accounts, however, is any indication that Martha or Julie sought to substantiate their interpretations of these "refusals", by entering the life worlds of two men with little spoken communication.

4.3 | Unhealthy choices

In Excerpt 5 (see Box 3), Debbie, a senior support work with over 6 years of experience, has just been asked what it is like to say "no" when Ms Lee asks for foods likely to undermine efforts to reduce her weight (see Box 3, Excerpt 5). Debbie describes how, in order to

Box 2 Refusals to Eat and the Risk of Undernutrition

Excerpt 3.

Martha: The choice comes into it if he refuses it and wants it blended. That's his choice to have it blended. You've offered it to him in the normal form, chopped up, you know you've offered it to him like that – how me and you would eat it – he's refused it; you then blend it. That's his choice to have it blended. Sometimes he'll refuse that completely because he doesn't want the savoury, and we'll go straight to the pudding. Because sometimes he chooses not to eat his main meal that's his choice as far as we see it. [38 years old; profound learning disability; no spoken communication]

Excerpt 4.

Julie: And the games we play. [pause] Let's put it this way, if we took the plate away, as often as he tries to get us to, he'd weigh about three stone. Wouldn't he [addressing a colleague]. But then, it's so strange, because he's been playing these games, and then the whole meal will go.

Inter: So, you really think it's kind of... that he's manipulating you.

Julie: Oh definitely, yeah definitely because like sometimes he can't even look at the plate, can he [turning to the same colleague]. Sometimes you can get away with having the plate on the corner of the table and putting the spoon on the table and he'll eat it. And other times you've gotta hold it behind him so he can't see the plate at all. Or sometimes the plate can be in front of him and he'll just... You'll have to load the spoon up and then he'll pick the spoon up off the plate. So, you have to go through all the different games until you find the one that's appropriate for that day. [87 years old; moderate learning disability; limited communication]

avoid offering a choice and then "having to say"no" to those kinds of things [unhealthy foods]," she and colleagues offer Ms Lee a choice between several preselected meals. Debbie styles this an "informed choice." Although contrary to how this term is usually understood, it is Debbie and her co-workers, not Ms Lee, who are appraised of the risks and benefits of choosing some foods over others. Excerpt 6 (see Box 3), the final excerpt, also concerns the possibility that a service user might choose unhealthy foods. Daniel, with 5 years of DSS experience, asserts that Mr Jonathon Bruce has a liking for takeaway meals. This prompts the interviewer to ask about the possibility of Mr Bruce wanting to eat takeaways every day: "Would he be able to do that [pause] I mean where does the choice stop" (see Box 3, Excerpt 6). Responding to a question about possible limits to service user choice, Daniel cites a "duty of care" and then turns to Mr Bruce. Involving him in the discussion, Daniel seeks Mr Bruce's

Box 3 Unhealthy Choices

Excerpt 5:

Debbie: It is quite hard because, again, you know, we want to offer as much choice and independence as we can without having to say 'no' to those kinds of things [unhealthy foods]. What we tend to do now is give her a choice of maybe two or three things that she can eat. So quite often the service users all sort of choose their own meals in the evenings now. So anyway, there'll often be three or four different types of food being cooked and we will often ask her "Do you want sausage and mash or maybe the chicken casserole or the chicken curry" and she'll choose that way. So, it's kind of to give her an informed choice. Rather than this huge choice of what she can have, rather than almost saying: "what do you want ... Oh no you can't have that" [57 years old; severe learning disability and early onset dementia; limited spoken language].

Excerpt 6:

Daniel: It comes into duty of care as well though, doesn't it.
Inter: Yeah, and that's an interesting one isn't it.

Daniel: Yeah. You're [turning to Mr Bruce] quite sensible in the fact that you would listen to what staff advised. And I think to be fair, Jonathon would get quite bored if he had Chinese and Indian every day, wouldn't you.

Mr Bruce: Yeah, I would.

Daniel: He likes it as a treat, as something to look forward to, but fortunately I think he's got the capacity to appreciate that that's not ideal every single day, and he likes too many other foods.

Inter: So, it's not a real problem.

Daniel: No. I don't ... I think we can safely say that would never be an issue, hey Jono.

Mr Bruce: No. [37 years old; mild learning disability; verbal communication]

endorsement of his observations that he is "quite sensible in the fact that you would listen to what staff advised" and that he "would get quite bored if he had Chinese and Indian every day." Following Mr Bruce's validation of these observations, Daniel states that Mr Bruce sees takeaways as a "treat," that he has the capacity to "appreciate that that's not ideal [takeaway food] every single day", and that "he likes too many other foods." Showing that she understands the implications of Daniel's remarks, the interviewer says, "so, it's not a real problem [choosing to eat takeaways every day]." Daniel responds by again seeking Mr Bruce's endorsement, "I think we can safely say that would never be an issue, hey Jono," and receives the reply: "No." Although Daniel invokes a "duty of care," with the implication that he might have to place limits on what Mr Bruce can choose, he neither describes the attributes of that duty nor its practical application.

Rather, he makes a number of observations as to why Mr Bruce is unlikely to choose to eat takeaways every day. In Excerpts 5 and 6, the respondents confront the possibility of service users making unhealthy dietary choices. For Debbie, this entails restricting Ms Lee to choosing from a range of preselected "healthy options." Daniel, by contrast, constructs an image of Mr Bruce as someone who is unlikely to make consistency unhealthy choices. So, while it is Daniel who cites a duty of care, he, unlike Debbie, does not appear to be exercising that duty.

What, more generally, can these six excerpts tell us about how DSS might be defining good practice with respect to mealtime support?

5 | DISCUSSION

These six excerpts, while certainly not exhaustive of the phenomenon, illustrate ways in which DSS understand competent care when a person's wishes and choices conflict with the imperative to provide safe and adequate nutrition and hydration. These excerpts are seen to focus on three specific risks: choking and aspiration; undernutrition; and unhealthy eating. The excerpts demonstrate DSS are invoking a range of contextual factors: advice from clinicians (Excerpts 1 and 2); the right of service users to choose (Excerpts 1, 2, 3, 5 and 6); a service user's preferences (Excerpts 1, 3 and 6); the loss a service user might experience if their wishes are not respected (Excerpts 1 and 5); the (in)capacity of a service user to weigh up potential risks (Excerpts 2 and 6); how a service user communicates choice (Excerpt 3); the importance of ensuring a service user eats (Excerpts 3 and 4); the constituents of a healthy diet (Excerpts 5 and 6); and a responsibility or duty to protect a service user's health (Excerpts 1, 2 and 6) that might involve respecting a person's autonomy (Excerpt 1) or overriding an expressed preference in order to ensure a person's safety (Excerpt 2). Some courses of action seem to promote safe and adequate nutrition and hydration over choice (Excerpts 2 and 5), while others seem potentially riskier (Excerpts 1 and 3); others to balance competing imperatives (Excerpts 1 and 6) or sidestep the issue of choice altogether (Excerpt 4). The excerpts also illustrate how providing mealtime assistance can encompass a wide range of activities, such as supervising a service user in case of choking (Excerpt 1); denying a person something they want (Excerpt 2); chopping up and blending food (Excerpt 3); repeatedly presenting and re-presenting a meal until it is eaten (Excerpt 4); preparing three or four different meals (Excerpt 5); and offering dietary advice (Excerpt 6). This variation in response, to when a person's wishes and choices conflict with the provision of safe and adequate nutrition and hydration, indicates there is no predetermined, or prescribed, response when managing tensions between protecting a person from harm and respecting their autonomy. As such, DSS are free to exercise a degree of creativity or imagination in how they understand and react to these situations.

This is evidenced by the "compromise," which allows Mr Davies to eat his favourite food despite the risks this entails (Excerpt 1); the

“games” that are played in order to get Mr Shaw to eat (Excerpt 4); as well as the preselection of the foods so that Ms Lee can choose a healthy meal (Excerpt 5). What, however, should one make of Martha's claim that Mr Preston's refusals to eat mean that he is *choosing* to have his food blended or even to move straight on to a pudding (Excerpt 3)? When compared to Mandy's assertion of Mr Davies' right to choose (Excerpt 1), Debbie's account of wishing to ensure that Ms Lee can choose her food (Excerpt 5) and Daniel's description of Mr Bruce as someone who makes sensible choices (Excerpt 6), one can see the significance that DSS give to the idea of choice. It is also apparent, however, that there is considerable flexibility in how DSS operationalize that choice. These four accounts also reveal that the severity of a person's disability might be deployed by DSS in depicting how they manage tensions between a person's autonomy and any responsibility to protect service users from harm. Mr Preston (Excerpt 3) has no spoken communication and a profound disability, while Mr Bruce (Excerpt 6) has only a mild disability meaning that responding to advice and making an informed choice is a distinct possibility.

While these excerpts clearly signal an explicit commitment among DSS to the idea of service user choice, little was said anywhere in the entire body of data about specific instances, ideas or practices for supporting service users to actually make an informed choice. Daniel (Excerpt 6) is the only respondent who gave any indication that a service user might receive advice from DSS. Rather than providing support with decision making, DSS appeared, in some cases, to present themselves as promoting service user choice, while, at the same time, acting paternalistically to protect that person from any harmful consequences. Thus, while Mandy asserts Mr Davis' right to eat toast, she cuts it into small pieces and observes him as he eats without apparently consulting him (Excerpt 1). Similarly, Debbie, while allowing Ms Lee to choose what she eats, preselects the range of meals on offer to ensure that Ms Lee eats healthily (Excerpt 5); while Daniel's allusion to his duty of care suggests that he would intervene should Mr Bruce wish to have takeaways at every meal (Excerpt 6). This practice of respecting and promoting service user choice while also acting paternalistically may, as Debbie suggests, avoid the “hard” work of offering a choice but then having to say, “Oh no you can't have that” (Excerpt 5).

What this discussion reveals is that competent mealtime support is not a binary distinction between respecting service users' wishes and ensuring safe and adequate nutrition and hydration. Rather, mealtime support is a complex responsibility, in which DSS are looking beyond choice and safety to find workable solutions to an everyday dilemma.

6 | CONCLUSION

SLTs, managers and supervisors in residential services, along with the bodies responsible for setting standards and regulating care practices, need to look beyond simple ideas of choice and safety. Mealtime support is a complex responsibility. DSS are engaged in finding workable solutions to everyday dilemmas, a fact that

needs to be recognised in the development of models of care and, in the training received by DSS. Ideally, this training should address how best to enable the people being supported to develop their capabilities (Gawande, 2014), and how responsibility for any risk might be shared (Mol, 2006). For then, and perhaps only then, can services begin to address the incidence of diet-related ill-health among men and women (Tyrer & McGrother, 2009; Glover & Evison, 2013) while also furnishing men and woman with intellectual disability with opportunities for self-expression.

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How to cite this article: Redley M. Mealtime support for adults with intellectual disabilities: Understanding an everyday activity. *J Appl Res Intellect Disabil*. 2020;00:1–7. <https://doi.org/10.1111/jar.12790>